

Original article ■

Effect of Child's Cerebral Palsy on the Mother: a Case Control Study in Ahvaz, Iran

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SUMMARY

Quality of life (QOL) in families can be affected when a child has cerebral palsy (CP). The aim of this research was to determine the effect of a child's disability on the mother's quality of life by comparing mothers of children with CP and mothers of normal children.

Two sample groups were chosen from a total of 42 mothers to answer a short-form health survey (SF-36) questionnaire. The first group included 21 mothers of children with cerebral palsy who were referred to the speech therapy clinic of Jundishapur University of Medical Sciences in Ahvaz. The second group consisted of 21 mothers of normal children living in Ahvaz. T-tests by SPSS were used for statistical analysis.

There were significant differences in all domains of QOL between mothers of healthy children and mothers of children with cerebral palsy ($p=0.001$).

This research found that the quality of life of mothers of children with CP was significantly different compared to mothers of healthy children. Therefore, appropriate planning is necessary to improve their quality of life in different domains.

Key words: quality of life, mothers, cerebral palsy, Iran

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INTRODUCTION

Quality of life (QOL) describes an individual's perception of his or her position in a context in relation to concerns and goals (1). A problematic child may cause physical and psychological stress on the family involved (2-6). This affects the family's daily life (7) and can induce a sense of unworthiness, guilt, and fatigue for family members (8), especially mothers (9). Parents of children with cerebral palsy (CP) experience physical and social difficulties. The family may lack a sense of well-being (10-12) and parents can experience musculoskeletal pain (13). Siblings of children with the condition may also be affected (14, 15). A few studies have been done on mothers of children with developmental disorders and CP (7, 16-18). The aim of this study was to evaluate QOL for mothers of children with CP and to compare their QOL evaluations with those from mothers of normal children.

MATERIAL AND METHODS

This was a case control study. Convenient samplings were used to select 42 persons divided into two groups in Ahvaz, Iran. The case group comprised 21 mothers of children with cerebral palsy who had been referred to the speech-therapy training clinics at the Ahvaz University of Medical Sciences in autumn 2009. The control group comprised 21 mothers of healthy children in Ahvaz. Mothers from both groups completed the short form for quality of life (SF-36). This questionnaire has satisfactory performance as a standard tool for the international Medical Outcomes Study (MOS) to learn about a population's health, evaluate clinical interventions, and study the cost-effectiveness of interventions and policy-making evaluations of health.

To assess quality of life, there are different tools, such as WHO-QOL-100, Sf-20, Sf-12, and SF-36 (19) but analyses have shown that SF-36 was a reliable instrument. It is applicable in different cultures and has separation capabilities among different groups based on age, geographic region, gender, and socioeconomic status (20), making it suitable for our research.

Note that the Iranian version of SF-36 was used. Its validity was confirmed on 4.163 healthy subjects in Tehran, Iran. Its convergent validity is more than 0.4 (0.58 to 0.95) and Cronbach's alpha coefficient is reported from 77.0 to 90.0. The SF-36 questionnaire has 36 questions that examine various dimensions of QOL such as physical functioning, physical limitations, role limitations due to emotional problems, energy/fatigue, emotional well-being, social functioning, pain, and general health (20).

The mothers of children with cerebral palsy were presented with a necessary description of the research process. After we received their consent, we collected demographic information and the SF-36 questionnaire was administered at the same session. Mothers of healthy

children were recruited from among relatives of children with cerebral palsy who were at an age similar to the age of mothers of children with cerebral palsy. For ethical reasons, information was captured anonymously and consent and willingness to participate in the study were required before a mother completed the form. If any parent declined to participate, information was not taken from them. In this study, any subject showing limitations such as low maternal education, problems communicating in Farsi language, and any lack of proper understanding of the questionnaire was excluded. Data collected were analyzed by SPSS v. 16 (SPSS Inc. Chicago, Ill., United States of America) and independent T-tests.

RESULTS

Forty-two mothers participated in the research. The mean age of mothers in this study was 31.50 ± 5.05 in the group of mothers with children with cerebral palsy and 29.50 ± 5.5 in the group of mothers of healthy children. All children with CP were quadriplegic and sixty percent of them in this group were male. The mean difference for level of QOL in various aspects between the two groups was significant: the mean for QOL in the group of mothers of healthy children was 74.93 ± 6.62 - higher than for mothers of children with cerebral palsy, which was a mean of 47.13 ± 11.11 ($p=0.001$) (Table 1).

Table 1. A comparison between the quality of life of mothers of children with cerebral palsy and mothers of healthy children

INDEX statistical variable	Mean &SD in the group of mothers with healthy children	Mean &SD in the group of mothers with childrenwith cerebral palsy	P
Physical functioning	72.23 ±13.68	41.82 ±17.09	0.001
Role limitations due to physical health	80.88 ±18.81	36.76 ±30.76	0.008
Role limitations due to emotional problems	86.27 ±20.61	49.01 ±23.1	<0.001
Energy/ fatigue	59.41 ±5.83	48.23 ±9.17	0.001
Emotional well being	72.17 ±7.31	54.11 ±16.30	0.002
Social functioning	67.64 ±14.69	51.47 ±14.57	0.002
Pain	90.88 ±13.04	47.50 ±17.80	0.001
General health	67.94 ±13.25	48.23 ±12.27	0.003
Overallquality of life	74.93 ±5.62	47.14 ±11.11	0.008

DISCUSSION

This study confirms a significant difference between quality of life of mothers of children with cerebral palsy compared with quality of life among mothers of healthy children. The results show that a child with a developmental disorder like CP affects various aspects of quality of life. Physical or mental disabilities at birth or during growth and development force the family to confront stages of shock, denial, and guilt that can eventually lead to stress and anxiety for the whole family. CP rehabilitation programs for children utilize a multidisciplinary approach where members of a team are selected with respect to a child's age, developmental level, severity of impairment, and availability of services. Yet, in all cases, the child's family remains at the center of the treatment team and a child's challenges can be a great source of stress to the family that may impact quality of life. Due to the mother's central role in family life and responsibilities for childcare, she will experience a higher level of stress and anxiety (21).

A study by Davis et al. showed significant differences between the quality of life for parents of children with illness and parents of healthy children (10). Other studies have demonstrated that families with a disabled child experience additional levels of psychological stress, depression, and anxiety (22). Such situations can also increase the prevalence of numerous diseases and pain/discomfort (18). These diseases and disorders dramatically reduce the quality of life for the mothers. Accordingly, these negative effects amount to a maternal disease

and impaired quality of life for mothers of children with CP more than for other mothers.

A study by Khayatade Mahani showed that a child with CP or mental retardation reduced various aspects of QOL (18), which is consistent with results of this study.

Other studies have evaluated the quality of life of mothers with sick children and compared results with mothers of healthy children (7, 23-25). Those studies showed similar results to those from this study, indicating significant differences between quality of life for mothers of children with CP and others.

Other research by Yee Lim et al. (26) and Diwan, et al. (27) reported that mothers of children with cerebral palsy have impaired health-related QOL. Okurowska-Zawada et al. (25) studied 40 parents of children with cerebral palsy and found that half of the parents described their quality of life as good and felt satisfied with their health. These parents had adapted well and accepted their situation. Continuity and resilience in these families were higher than in families with healthy children, which reduced negative effects such as depression and stress.

Eker et al. studied quality of life among mothers of healthy children compared with mothers of children with cerebral palsy. The results showed that profiles of mothers of children with cerebral palsy were different and lower than those of mothers of children with only mild physical problems (17). Several possible reasons have been presented to account for the difference in QOL between mothers of children with CP and mothers

of healthy children and some of these are mentioned below.

As stated, mothers of children with cerebral palsy suffer more stress than mothers of healthy children. In addition to psychological pressure, stress, and depression, low quality of life for mothers of children with CP is related to concerns about their child's future. On the other hand, mothers of healthy children have more time to spend and can participate more fully in social activities, entertainment, and business. By contrast, mothers of children with problematic health conditions devote much of their time to their child's nutrition, health, treatment, rehabilitation, and exercise therapy. Moreover, there are increased costs imposed on households and inadequate funding from insurers in Iran, which increases financial pressure for these families. It particularly causes a decline in mother's quality of life, both physically and psychologically.

CONCLUSION

We found significant differences between quality of life for mothers of children with cerebral palsy and mothers of normal children. Appropriate planning is necessary to improve their QOL in different domains. For instance, participation in aerobics and yoga exercises, consultation with a psychologist, and group discussions can be helpful. Finding ways to enhance quality of life would be a good direction for future research.

Acknowledgments

The authors thank the speech therapy clinics of School of Rehabilitation Sciences of Ahvaz Jundishapur University of Medical Sciences (AJUMS) and the vice-chancellor for research affairs of AJUMS for their support of and contributions to this study. We also appreciate the assistance of the Research Consultant Center (RCC). There is no conflict of interest to be declared.

References

1. World Health Organization. Measuring Quality of Life: The Development of the World Health Organization Quality of Life Instrument (WHOQOL). Division of Mental Health, World Health Organisation, Geneva, Switzerland. 1993.
2. Uskun E, Gundogar D. The levels of stress, depression and anxiety of parents of disabled children in Turkey. *Disabil Rehabil* 2010; 32(23): 1917-27.
<http://dx.doi.org/10.3109/09638281003763804>
3. Glenn S, Cunningham C, Poole H, Reeves D, Weindling M. Maternal parenting stress and its correlates in families with a young child with cerebral palsy. *Child Care Health Develop* 2009; 35(1): 71-8.
<http://dx.doi.org/10.1111/j.1365-2214.2008.00891.x>
4. Ong LC, Afifah I, Sofiah A, Lye MS. Parenting stress among mothers of Malaysian children with cerebral palsy: predictors of child- and parent-related stress. (Comparative Study). *Ann trop paediatr* 1998; 18(4): 301-7.
5. Glasscock R. A phenomenological study of the experience of being a mother of a child with cerebral palsy. *Pediatr Nurs* 2000; 26(4): 407-10.
6. Fonseca A, Nazare B, Canavarro MC. Parental psychological distress and quality of life after a prenatal or postnatal diagnosis of congenital anomaly: a controlled comparison study with parents of healthy infants. *Disabil Health J* 2012; 5(2): 67-74.
<http://dx.doi.org/10.1016/j.dhjo.2011.11.001>
7. Bumin G, Günel A, Tükel P. Anxiety, depression and quality of life in mothers of disabled children. *S.D.Ü. Týp Fak Derg* 2008; 15(1): 6-11.
8. Hedov G, Anneren G, Wikblad K. Self-perceived health in Swedish parents of children with Down's syndrome. *Qual Life Res* 2000; 9(4): 415-22.
<http://dx.doi.org/10.1023/A:1008910527481>
9. Hastings RP, Kovshoff H, Brown T, Ward NJ, Espinosa FD, Remington B. Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism* 2005; 9(4): 377-91.
<http://dx.doi.org/10.1177/1362361305056078>
10. Davis E, Shelly A, Waters E, Boyd R, Cook K, Davern M, et al. The impact of caring for a child with cerebral palsy: quality of life for mothers and fathers. *Child Care Health Develop* 2010; 36(1): 63-73.
<http://dx.doi.org/10.1111/j.1365-2214.2009.00989.x>
11. Raina P, O'Donnell M, Rosenbaum P, Brehaut J, Walter SD, Russell D, et al. The health and well-being of caregivers of children with cerebral palsy. *Pediatrics* 2005; 115(6): e626-36.
<http://dx.doi.org/10.1542/peds.2004-1689>
12. Brehaut JC, Kohen DE, Raina P, Walter SD, Russell DJ, Swinton M, et al. The health of primary caregivers of children with cerebral palsy: how does it compare with that of other Canadian caregivers? *Pediatrics* 2004; 114(2): e182-91.
<http://dx.doi.org/10.1542/peds.114.2.e182>
13. Kaya K, Unsal-Delialioglu S, Ordu-Gokkaya NK, Ozisler Z, Ergun N, Ozel S, et al. Musculo-skeletal pain, quality of life and depression in mothers of children with cerebral palsy. *Disabil Rehabil* 2010; 32(20): 1666-72.
<http://dx.doi.org/10.3109/09638281003649912>
14. Kuo, YC, Geraci LM. Sister's Caregiving Experience to a Sibling with Cerebral Palsy- the Impact to Daughter-Mother Relationships. *Sex Roles* 2012; 66: 544-57.
<http://dx.doi.org/10.1007/s11199-011-0098-y>

15. Kuo YC, Lach LM. Life decisions of taiwanese women who care for a sibling with cerebral palsy. *Health Care Women Int* 2012;33(7): 646-65.
<http://dx.doi.org/10.1080/07399332.2012.673655>
16. Ones K, Yilmaz E, Cetinkaya B, & Caglar N. Assessment of the quality of life of mothers of children with cerebral palsy (primary caregivers). *Neurorehabil Neural Repair* 2005; 19(3): 232-37.
<http://dx.doi.org/10.1177/1545968305278857>
17. Eker L, Tuzun EH. An evaluation of quality of life of mothers of children with cerebral palsy. (Comparative Study). *Disabil Rehabil* 2004; 26(23):1354-9.
<http://dx.doi.org/10.1080/09638280400000187>
18. KhayatadehMahani M. A comparative Study about quality of life in Mothers of children with cerebralpalsy, mental retardation and mothers of normal children. *Daneshvar Medicine Journal* 2009;16(83): 49-58.
19. ToubaeiSh, Hadi N, Hedayati A, Montazeri A. Comparison of health related quality of life between bipolar patients and healthy controls. *J Fundamentals Mental Health* 2012; 14(1): 54-63.
20. Montazeri A, Goshtasebi A, Vahdaninia M, Gandek B. The Short Form Health Survey (SF-36): translation and validation study of the Iranian version. *Qual Life Res* 2005; 14(3):875-82.
<http://dx.doi.org/10.1007/s11136-004-1014-5>
21. Ryde Brandt B. Anxiety and depression in mothers of children with psychotic disorders and mental retardation. *Br J Psychiatry* 1990; 156:118-21.
<http://dx.doi.org/10.1192/bjp.156.1.118>
22. Olsson MB, Hwang CP. Depression in mothers and fathers of children with intellectual disability. *J Intellect Disabil Res* 2001; 45(Pt 6): 535-43.
<http://dx.doi.org/10.1046/j.1365-2788.2001.00372.x>
23. Arnaud C, White-Koning M, Michelsen SI, Parkes J, Parkinson K, Thyen U, et al. Parent-reported quality of life of children with cerebral palsy in Europe. *Pediatrics* 2008; 121(1):54-64.
<http://dx.doi.org/10.1542/peds.2007-0854>
24. Bonomi AE, Patrick DL, Bushnell DM, Martin M. Validation of the United States' version of the World Health Organization Quality of Life (WHOQOL) instrument. *J Clin Epidemiol* 2000; 53(1):1-12.
[http://dx.doi.org/10.1016/S0895-4356\(99\)00123-7](http://dx.doi.org/10.1016/S0895-4356(99)00123-7)
25. Okurowska Zawada B, Kułak W, Wojtkowski J, Sienkiewicz D, Paszko Patej G. Quality of life of parents of children with cerebral palsy. *Prog Health Sci* 2011; 1(1): 116-23.
26. Melisa Seer Yee Lim, CheePiau Wong. Impact of cerebral palsy on the quality of life in patients and their families. *Neurol Asia* 2009; 14: 27-33.
27. Diwan DS, Chovatiya DH, Diwan DJ. Depression and Quality Of Life in Mothers of Children with Cerebral Palsy. *NJIRM* 2011; 2(4): 11-3.

UTICAJ CEREBRALNE PARALIZE DETETA NA ŽIVOT MAJKE: STUDIJA SLUČAJA U AHVAZU, IRAN

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Sažetak

Kvalitet života porodica koje imaju dete obolelo od cerebralne paralize (CP) može biti značajno izmenjen. Cilj ovog istraživanja bio je da se ispita uticaj invaliditeta deteta na kvalitet života majke tako što su upoređivane majke dece sa cerebralnom paralizom i majke zdrave dece.

Istraživanje je obuhvatilo dve grupe od ukupno 42 majke koje su odgovorile na kratak upitnik (SF-36). Prva grupa je uključila 21 majku dece sa cerebralnom paralizom koja su bila upućena na Kliniku za terapiju govora u okviru Jundišapur Univerziteta Medicinskog fakulteta u Ahvazu. Drugu grupu je sačinjavala 21 majka zdrave dece koja su takođe živela u Ahvazu. Rezultati su obrađeni kompjuterskim programom za statističku analizu podataka (SPSS) i korišćen je T-test.

Utvrđene su značajne razlike u svim domenima kvaliteta života između majki zdrave dece i majki dece sa cerebralnom paralizom ($p=0.001$).

Istraživanjem je utvrđeno da je kvalitet života majki dece sa cerebralnom paralizom značajno izmenjen u poređenju sa kvalitetom života majki zdrave dece. Stoga je potrebno uraditi detaljno planiranje kako bi se poboljšao njihov kvalitet života u različitim domenima.

Ključne reči: kvalitet života, majke, cerebralna paraliza, Iran